



ELF EUROPEAN
LUNG
FOUNDATION

European Lung Foundation

Youth Group Strategy

2024 - 2026



Our background

Founded in 2000, the [European Lung Foundation](#) (ELF) is a patient-led organisation that brings patients and the public together with healthcare professionals. It has a volunteer patient network of more than 350 people, as well as Patient Organisation Network with more than 200 respiratory organisations.

ELF strives to raise awareness about lung conditions, to represent as many patients and conditions as possible and make their voice heard at an EU level. For this reason, it has created [Patient Advisory Groups](#) (PAGs) for a wide range of lung conditions, such as asthma, bronchiectasis, covid-19, sleep apnoea, etc. The members of the groups share a common passion; improving healthcare and treatment across Europe. To do so, they share their views on living with their condition, they provide their input to EU projects, surveys, and they contribute to research.

Representing as many people as possible is one of the main goals of ELF. To ensure that we are meeting the needs of young people with a lung condition, we decided to launch our [Youth Group](#) (hereafter the Group) in 2024 and to promote young people's voices. We firmly believe that young people have a lot to give to the lung patient community, to healthcare professionals and to projects that focus on lung health.

What is the ELF Youth Group?

It is a group of people 16-24 years old who have a lung condition and care about lung health. The purpose of the Group is to identify and advocate for the needs of young people with lung conditions.

Our approach so far

ELF has either led or participated in multiple projects and campaigns, focusing on young people

- [Healthy Lungs for Life for Schools](#), to educate young people about the importance of lung health.
- Lung Health 4 Life, an EU project about spirometry testing in schools.
- [FreshAir 4 Life](#), an EU-funded project about tobacco and air pollution exposure in mid- to late adolescents in disadvantaged populations.

Why the ELF Youth Group is important

Your input, lived experience and opinion are very important!

- You can provide fresh and unique insights.
- You can empower other young people with lung conditions to contribute to research and policy making.
- You can challenge possible stigma and raise awareness.
- You can contribute to the creation of a safe environment where young people feel comfortable discussing their experiences.

Our 2024 – 2026 strategy

Our strategy's main goal is to ensure that the opinions and experiences of young patients are taken into account on a European policy level. Through empowering patients and giving them the means to become responsible and impactful advocates and by strengthening patients and healthcare professionals' collaboration. We hope to achieve our goals with the formation and the re-evaluation, when needed, of our strategy.

Strategic goal 1: Identifying the challenges and needs of young patients

ELF wants to understand young patient's lived experiences, opinions, needs, as well as the challenges they face as adolescents or young adults who live with a lung disease. To do this, it will create a network of young patients (16-24 years old) who will share their experience. More specifically, they will explore a wide range of issues, such as the challenges that their condition might have caused to their studies, activities, socialisation and mental health. Furthermore, they will discuss on the challenges of transitioning from child to adult care, possible diagnosis challenges, access to medicine and care.

Young patients will be able to do the above by

- participating in online meetings of the Group.
- answering anonymous surveys.
- communicating with the other members of the Group and the ELF staff in other, more informal ways.

Strategic goal 2: Making the voice of young patients heard

ELF aims to build a supportive and empowering community through this group. The empowerment of adolescents and young adults will contribute to shaping responsible citizens of tomorrow. Once identifying common experiences, challenges and aspirations concerning lung diseases, the Group will take action to reach out to a wider audience, targeting other young people, other lung patients, policy makers and the general public.

This will happen in various ways, such as

- launching a social media campaign that will promote stories, perspectives and recommendations.
- having online meetings with relevant healthcare professionals to start a dialogue that could inspire both sides (patients and professionals).
- enriching the materials that ELF produces, such as fact sheets.
- reviewing papers of ELF and the European Respiratory Society (ERS).
- participating in interviews.
- writing articles or commenting on them.
- producing materials that are young person-friendly.
- providing input for projects related to young people.
- participating in other opportunities that might arise.

Strategic goal 3: Developing advocacy skills

Advocacy is empowering people to act on their own behalf. ELF believes that it is very important for patients to be able to advocate for several reasons; to ensure that their care is tailored to their specific needs and thus increasing the chances of better health outcomes, to have an active role

in their healthcare decisions and ensure mutual understanding with their health carers, to better manage their condition independently, to raise awareness for the general public and other patients, to improve healthcare system.

To develop its advocacy skills the Group

- will become familiar with the [European Patient Ambassador Programme \(EPAP\)](#), a free, online, self-learning ELF programme that introduces patients and carers to some of the basic skills and knowledge needed to represent themselves and others successfully.
- Will learn more about patient advocacy from ELF advocates, such as [ELF Chair](#) and other patients that participate in [ELF PAGs](#).
- Will put in practice their knowledge by participating in the ELF activities mentioned above.